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ABSTRACT

This keynote address discusses the importance of having a dream, or shared vision, of the future of individuals with severe disabilities within society. A dream of a social environment that encourages and enables communication with individuals with severe disabilities is proposed. A plan for turning that dream into reality focuses on effective communication partnering, where all members of society have the desire and skills needed to communicate effectively with individuals with severe disabilities. The presentation concludes with a journey on a flying machine, which provides an overview perspective of how the field has evolved through various emphases, including communication units (pre-1957 period), rules (1960s), communicative intent (early 1970s), communicative function (mid 1970s), dyadic interaction (late 1970s), and the ecological interrelationship of individual and environmental variables (1980s). The speech then urges the melding or merging of all previous phases if the dream of full inclusion and the scheme of effective partnering are to be attained. (DB)

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Dreams, Schemes, Teams, Flying Machines and Persons with Severe Communication Disabilities

A Keynote Address
by
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This keynote address discusses the importance of having a dream, or shared vision, of the future of individuals with severe disabilities within our society. A dream of a social environment that encourages and enables communication with individuals with severe disabilities is proposed.[1] To turn that dream into concrete reality, however, requires a scheme, or specific plan. The scheme suggested by the author is one of effective communication partnering, where all members of society have the desire and skills needed to communicate effectively with individuals with severe disabilities. Effective, informed teams will be needed to enact the scheme and accomplish the dream. The keynote address concludes with a journey on a flying machine, which provides an overview perspective of where the field has been, where it currently is, and where it might go in the future, if the dream of full inclusion and the scheme of effective partnering are to be attained.

In 1988, at the OSEP-NEC*TAS Partnership Conference in this city, Ann Kaiser delivered a paper entitled "Dreams, Schemes, Flying Machines and the Law: New Perspective on P.L. 99-457." Not only was her presentation excellent, but I found her title and ideas exciting. To Ann Kaiser, I owe my own adaptation of that title: *Dreams, Schemes, Teams, Flying Machines, and Persons with Severe Communication Disabilities.*

Dreams

Dreams are important. By definition, a dream is "a visionary creation of a strong desired goal or purpose." A dream is the mental image of the idealized version of a desired result. Dreams are the seeds from which great plans and mighty movements evolve. Dreams can be the unique creation of an individual or the shared dream of a group of persons with similar concerns and goals.

We have a dream about a social environment that encourages and enables communication with individuals with severe disabilities. In 1992, the National Joint Committee for Meeting the Communicative Needs of Persons with Severe Disabilities issued guidelines that contain a "Communication Bill of Rights." One

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component of this document is an assertion of the right of individuals with disabilities to surroundings that "expect and encourage (their participation) as full communicative partners with other people, including peers" (National Joint Committee, 1992, p. 3). This means that it is not enough for us to teach the skills necessary for communication to individuals with disabilities; we must also create an environment in which there will be people who desire, and know how, to interact with any person, regardless of that person's level of function. And just how do we create this environment in which people will have this desire? *Schemes*, folks. We need a scheme.

Schemes

A scheme is the bridge between the dream and reality. A scheme is a plan, a strategy, a program of action. There are four key characteristics of an effective scheme:

1. keep it as simple as possible;
2. make it flexible so that responses to changes in the system can be accommodated;
3. consider the human factor, the most important level of any system; and
4. build in responsiveness at key human points, allowing those involved to have some control in their interactions in the system.

Our dream of a responsive and encouraging environment for persons with disabilities requires a plan if it is to move to reality. We cannot merely talk about how important it is to provide effective communication systems for all persons; we must devise a plan to make it happen. Let's figure out what to scheme about. I suggest *effective (communication) partnering*. Next, we'll sketch out the scheme -- our strategies for bringing about effective (communication) partnering. Then we'll carry out the scheme by *doing it* (to borrow a well-used phrase from Nike).

There are some potential barriers to this scheme. To enact the goals of the dream verbalized in the Communication Bill of Rights will *require a plan (scheme) for the education of all people who will potentially interact with, or affect those who interact with, persons with a severe disability*. This includes: the family; the extended family; educational, recreational, and vocational personnel; religious leaders; service personnel (e.g., the cashiers at McDonalds); and the public media personnel, to give a few examples. These individuals include a wide range of values, abilities, and concerns; to devise a scheme flexible enough to be responsive to all potential communication partners will be a major and difficult task but certainly not an insurmountable one. Let's *do it*.

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There is a need to create an accepting attitude among those who interact with the individual with a severe disability. Legislation such as the Americans with Disabilities Act can remove physical barriers, but statutes cannot generate sentiment. Our dream is not of a society that is creating accessibility and providing opportunities in grudging compliance with federal, state, and local mandates, but of a society that welcomes and includes individuals with disabilities in daily activities because it *wants* to. What will bring about that change? How will it happen? Whose responsibility is it to ensure that it happens?

Start with us, the transdisciplinary *team* of professionals.

Teams

All disciplines must share responsibility if we are to create and implement a scheme for effective partnering. Many fields touch the lives of individuals with disabilities. Warren and Reichle (1992) discuss the positive results of multidisciplinary input. It provides an abundant source of contributions to a singular set of goals. There is a negative side, however. As Warren and Reichle (1992) state, "This diffusion also leads to dissolution and lack of focus" (p. 2). Part of determining if a scheme is working is to keeping in mind our dream (focus). We must remind ourselves of what we are trying to get done. No scheme, no matter how elegant, is useful if it doesn't bring us to reality. It is important to conceptualize our dream in a concrete plan, specific to the needs of persons with severe disabilities and their families and to the abilities of us who must assume the responsibility for change. This means moving beyond the required planning (dictated by public laws) to meaningful planning (the desire to do it). Next, we must outline interim goals that reflect that meaning.

A shared language (good communication) is at the core of successful teamwork. The team needs a system of common definitions and terminology in order to communicate with each other while developing the scheme. We all need to "talk the same talk," which must be meaningful to the lay public (potential partners). What do we all mean by terms such as effective communication, quality of life, functional communication, full participant in, least restrictive, integrated, appropriate, reasonable, and inclusion? These terms are loaded with tremendous implications for individuals with severe disabilities and their families, as well as for society as a whole.

Before we can figure out how to make all these things happen, we need to know what it would look like if "effective (communication) partnering" were occurring for those individuals with whom we are concerned.

Flying Machines

We all know what flying machines are, but for now let's think of their function. Flying machines allow us not only to get from one place to another, but also to get above the "playing field,"

to get a broader view of what is below. In other words, they allow us to gain a perspective of where we've flown from and a perspective of what we may yet encounter and/or look forward to.

Now I would like us to get up out of the trenches for a moment and take a bit of a trip. The flying machine is going to take us on a mind trip through time. Our flying machine allows us to have a moment of clarity, to catch a glimpse of what we're doing in its critical context.

The flying machine will allow us to look back to the beginning efforts to improve the communication of individuals with severe disabilities. If we look at the communication intervention programs that have been published in the last half of the cnetury, we clearly find a mirroring of our history of what is known about child language behavior. Like it or not, that old adage of "give a child a hammer and he (or she) will pound everything in sight" is quite like the role that our intervention programs have taken and do take. With each new "hammer" that became available to us at a particular time, we pounded on every person with a communication disorder (mild to severe) within sight and sound. Although our hammers have taken on different hallmarks, depending upon the era and knowledge base, they continued to have one thing in common: our zeal for using them to the exclusion of the other possible approaches (Yoder, 1987).

There are several recognizable phases in which the focus of intervention shifted. During Phase I, or the *Unit Period* (pre-1957), we focused on the acquisition of units of sounds, words, and sentences. Articulation therapy and vocabulary building were the focus of the game. Phase II was the *Rule Period* (1960s), when we examined the knowledge a child had of the rules of language that governed how these sounds, words, and sentences were combined. We pushed morphology and syntax, and every child had to have control of the progressive "-ing" form and the past tense markers! During the Rule Period an argument surfaced as to whether there was a human innateness which was responsible for language development, or whether language was acquired because of reinforcing events within the environment. Additionally, the nativist/behaviorist argument brought forth the critical question of whether language could really be taught. Some of us believed at that time that, with a good supply of M&Ms, you could teach absolutely anything to anybody.

Next came Phase III, or the *Intent Period* (early 1970s), when "we became aware that these units and rules subserved the expression of meaning and intentions" (Yoder, 1987, p. 7). During this period, we became acutely aware of the conceptual underpinnings of utterances. In this phase, we returned to looking at the importance of the environment on language learning and use. Parents became important.

Following this was Early Phase IV, or the *Function Period* (mid 1970s). We began to attend to "the communicative functions of language ... (and) the perspective that acts of communication are present from the very beginning and are thus present before language, before

speech" (Yoder, 1987, p. 7). We discovered here that there was a utilitarian purpose to it all -- the communicative functions of language. We finally looked closely at the expression of early intentions, or what we interpreted as communicative intentions and functions. Enter now the acceptance of multiple modes of communication -- *augmentative and alternative communication*. Were we getting closer? Closer to effective communication?

Closely following was Late Phase IV, or the *Interaction Period* (late 1970s). We now concentrated on the dyadic relationship that involved the individual with a disability and his or her communicative partner and the conversational rules that governed the exchange between them. How to make "them" more interactive with whatever system of expression was a push. Then came Phase V, or the *Ecological Period* (1980s), in which we attempted to incorporate all aspects of the individual's verbal and nonverbal communication behavior, as well as examine other factors in the environment that made for richer communication.

And where, my friends, are we today? It appears we're still looking for that hammer that will make it all better, and, once we've found it, we'll have "effective communication."

Or will we?

From the flying machine it appears that we could be entering a new phase in our efforts to enhance the communication of individuals with (severe) disabilities. Perhaps the "new phase" we are about to enter is a melding or merging of all previous phases, an arena for all players to take part. Attending only to units, rules of language, meanings, intentions, and functions in the individual with a disability, however, is not enough. Until the person with a severe communication disability has as many communication partners available with whom to interact as you and I have, our dream is of little worth. We need to create: EFFECTIVE PARTNERING.

We've tried all of the above interventions individually. Some parts of some of them have worked and are working to bring about communication behaviors for persons with severe communication disabilities. How effective they may be, we're still not sure. Perhaps they are effective in the classroom, at home, and at McDonalds, but that is not enough. There still is not a societal attitude of (communication) partnering with all persons with severe (communication) disabilities.

Schein (1985) described a hierarchy of attitudes that societies have historically displayed toward individuals with disabilities. Schein's five stages range from the lowest level, Stage I or Total Rejection, to the highest level, State V or Egalitarianism. In Stage V, the most accepting and embracing attitude a society can hold toward its citizens with disabilities is to provide services for the individual with a disability that need not be justified on the basis of economics or proclaimed as a moral obligation, but that are willingly provided because individuals with disabilities are equal citizens deserving of equal opportunities.

If our dream is for our society to have an egalitarian attitude toward its citizens with severe communication disabilities, we must provide a scheme to bring it about (advocacy). Schein (1985) lists several suggestions for effective advocacy. Effective advocacy requires more than simply the desire to help -- it requires particular skills and strategies (schemes). Among these suggestions is "getting the act together" (p. 358). What is our current act? Can we make it effective (communication) partnering? Schein advises conducting a needs assessment (I think we know our needs) and gaining a consensus on issues and methods for obtaining the desired goals (scheming). This, we don't know. Schein stated that individuals with disabilities and their advocates "must decide what position they take with respect to their status in our society" (p. 356).

The distant horizon is a bit hazy and unclear, but we can see part of the way. What should we do about the future we can see? I trust that our collective wits at this symposium will provide some of that answer, some schemes to *provide effective partnering to bring about effective communication.* Let's climb out of the flying machine and develop a scheme, a plan for the team to make our community (society) full of persons who desire and want to be partners -- not just *communication* partners but *full participating partners* -- across all our main life activities. Then we will have accomplished effective partnering, which embraces effective communication.

A new hammer? Perhaps not, but maybe pounding in the right place.

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